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# Disclosure of HIV Status to Medical Providers: Differences by Gender, "Race," and Immune Function

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## SYNOPSIS

**Objective.** The authors used data from a larger study to explore differences by gender, self-reported racial identification, and immune function in disclosure of HIV-positive serostatus to medical providers (dentists, family doctors, and emergency room [ER] and obstetrics-gynecology [ob/gyn] providers).

**Method.** The authors analyzed interview responses from a convenience sample of African American and white men and women receiving HIV medical care at urban hospitals and clinics in St. Louis, Missouri.

**Results.** Of 179 respondents using at least one of three types of providers, 124 (69%) disclosed their HIV status to all applicable types of providers, 39 (22%) disclosed to only one or two types of providers, and 16 (9%) did not disclose to any of these types of providers. "Race" and CD4 count, but not gender, were independently associated with disclosure to dentists, family doctors, and ER providers in multivariate logistic regression analyses.

**Conclusions.** Differences in disclosure rates, especially among patients who may be asymptomatic, suggest a need for public health education of both medical providers and patients with HIV.

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In the past decade, researchers have devoted increasing attention to patterns of disclosure and reasons for nondisclosure of human immunodeficiency virus (HIV) status to sexual partners,<sup>1-9</sup> family members and other close individuals,<sup>10-16</sup> and employers.<sup>17-20</sup> Less close attention has been paid to disclosure to health care professionals.<sup>7,21-24</sup>

Although disclosure may be an important step in coping with HIV and can lead to receipt of important social support<sup>25</sup> and medical services,<sup>23,26</sup> many people who are HIV-infected refrain from disclosing their status to others until they become symptomatic or too sick to care for themselves.<sup>4,6,21,22</sup> Reasons cited for not disclosing one's HIV serostatus vary, including fears of rejection and disapproval from lovers and family members<sup>14</sup> and concerns about confidentiality and discrimination in regard to employers and health care professionals.<sup>17-20</sup>

A few studies have looked at differences in rates of disclosure to others by "race"<sup>14,24,25</sup> and level of immune function.<sup>20-22,24</sup> These studies found that African Americans or Hispanics were less likely than whites to disclose their HIV serostatus to others, and patients with better immune function were less likely than those with poorer immune function. Overall, little has been published about women's self-disclosure of HIV serostatus to medical providers.<sup>23,24,27,28</sup> To address this issue, we sought not only to describe patterns of self-disclosure among HIV-infected women but also to look at possible gender, "race," and immune-function differences in rates of disclosure to medical providers. Identification of different patterns of disclosure would enable health educators to target messages for specific groups of patients with HIV and for health care workers providing care for these patients. Early disclosure of one's HIV status to medical providers may not only to improve the diagnosis and treatment of HIV-related illnesses<sup>23</sup> but also help ensure timely receipt of vital medical and support services.<sup>26</sup>

Based on the findings of previous studies, we hypothesized that: (a) white men and women would be more likely than African American men and women to report having disclosed their HIV status to medical providers and (b) that people with poorer immune function would be more likely than people with better immune function to report having disclosed their HIV serostatus to medical providers. The first hypothesis follows from an expectation that African Americans would be more distrustful of the medical community than white Americans, at least in part as a result to the Tuskegee Syphilis Study.<sup>29,30</sup> The second hypothesis is based on study results showing that

asymptomatic patients are less likely than symptomatic patients to disclose their HIV status to medical providers not delivering HIV-related care.<sup>4,6,21,22</sup>

We tested these hypotheses using data from a study of factors associated with use and non-use of HIV medications.<sup>31</sup>

**Recruitment of participants.** At the end of June 1996, 2571 people in the St. Louis, Missouri, metropolitan area were known to the St. Louis Metro AIDS Program to be living with HIV/AIDS.<sup>32</sup> Of this group, 98% were either white (1089 men, 65 women) or African American (1119 men, 245 women).<sup>32</sup> From July through October 1996, we recruited a convenience sample of men and women (>16 years of age) from this population to participate in a study of psychosocial factors that might be associated with use and non-use of HIV medications.<sup>31</sup> We concentrated our recruitment efforts at clinics and hospitals that deliver medical care to the majority of HIV-infected patients in the St. Louis metropolitan area. Each participant received a \$10 gift certificate to a local grocery store. The study was approved by the Human Studies Committee at Washington University School of Medicine, and respondents' confidentiality was assured. The recruitment process is discussed in detail elsewhere.<sup>31</sup>

**Interviews.** Trained interviewers collected data in one-on-one, structured interviews. In addition to providing demographic data (gender, racial identification, and educational level) and medical data (CD4 T-lymphocyte cell counts, verified by medical records), participants completed several questionnaires, including one pertaining to disclosure of HIV status to family, friends, and various medical and social service providers.

**Definitions.** We asked respondents to identify their "race," giving them the following answer choices: "Caucasian," "African American," "Hispanic American," "Asian American," and "Other." (Hereafter, we will refer to Caucasian respondents as "white," following recommended publication guidelines for biomedical journals.)<sup>33</sup>

We also asked respondents to report their highest education level, giving these choices: "Some high school," "High school graduate," "Some college," "College graduate," "Some post-graduate study," and "Advanced degree."

The CD4 cell count is a marker of immune function. It is a computed index—the product of white blood cell count, the percent lymphocytes, and the percent of lymphocytes bearing the CD4 receptor—and is reported in cells per cubic millimeter (cells/mm<sup>3</sup>) of blood.<sup>34</sup>

The medical providers mentioned on the questionnaire were: dentist, family doctor, emergency room (ER) providers, and, for women, obstetrics and gynecology (ob/gyn) providers. Respondents indicated whether they had disclosed their HIV status to each type of provider, answering "Yes," "No," or "Does not apply."

## METHODS

For the data analyses, we used dichotomous variables for CD4 counts and educational level. We dichotomized CD4 counts as  $<200$  cells/mm<sup>3</sup> or  $\geq 200$  cells/mm<sup>3</sup> and educational level as  $<$ high school graduate or  $\geq$ high school graduate. We analyzed main effects of gender, self-reported racial identification, and CD4 count on disclosure to each applicable type of medical provider using two-tailed Fisher's exact tests. We excluded respondents who indicated that a particular type of provider did not apply to their situation from the analysis for that specific type of provider.

We also report the estimated relative risks (RRs) and 95% confidence intervals (CIs) for comparisons of rates of disclosure to each type of provider (comparing men to women, white respondents to African American respondents, and respondents with CD4 counts  $<200$  cells/mm<sup>3</sup> to respondents with CD4 counts  $\geq 200$  cells/mm<sup>3</sup>). In addition, we analyzed differences in disclosure rates by gender and by racial identification controlling for higher vs lower CD4 count. Finally, we performed multiple logistic regression analyses to identify the independent covariates of disclosure to each type of provider, entering CD4 count first, then allowing gender and racial identification to enter the models in a forward stepwise fashion

using the likelihood ratio criteria for variable entry (0.05) and removal (0.10).

## RESULTS

A total of 206 men and women were interviewed for the study. Demographic and immunologic data were available for 204 of the respondents who completed the disclosure survey. Because of insufficient numbers, we excluded from the analysis one man and one woman who self-identified as Hispanic. The final sample consisted of 202 respondents (Table 1).

Of the 106 men, 51 (48%) self-identified as white and 55 (52%) as African American. Of the 96 women, 21 (22%) self-identified as white and 75 (78%) as African American. The association between gender and self-reported racial identification was significant ( $\chi^2 = 15.12$ ,  $P < 0.001$ ).

The mean CD4 cell count for the sample was 307 cells/mm<sup>3</sup> (standard deviation [SD]  $\pm 287$  cells/mm<sup>3</sup>), with counts ranging from 0 cells/mm<sup>3</sup> to 1888 cells/mm<sup>3</sup>. A significantly greater proportion of men than of women had CD4 counts  $<200$  cells/mm<sup>3</sup> (RR = 1.94, 95% CI = 1.37, 2.73), but the difference by self-reported racial identification was not significant (Table 1).

Most of the sample (147/202, 73%) had at least graduated from high school. In preliminary analyses, we found education level to be related significantly to both gender ( $\chi^2 = 14.8$ ;  $P < 0.001$ ) and racial identification ( $\chi^2 = 7.8$ ;  $P = 0.006$ ) but not to CD4 cell count. Education level also was not associated with disclosure to any of the types of medical providers. Therefore, education level was not included in further analyses of the data.

**Table 1. Characteristics of HIV-positive African American and white survey respondents (N = 202)**

Characteristic	Total sample		CD4 count				P
			<200 cells/mm <sup>3</sup>		≥200 cells/mm <sup>3</sup>		
	N = 202		n = 91		n = 111		
	Number	Percent	Number	Percent	Number	Percent	
Gender							
Men . . . . .	106	52.5	62	68.1	44	39.6	< 0.001
Women . . . . .	96	47.5	29	31.9	67	60.4	
Racial identification							
African American . . . . .	130	64.4	57	62.6	73	65.8	0.660
White . . . . .	72	35.6	34	37.4	38	34.2	

NOTE: P values are for two-tailed Fisher's exact tests.

**Disclosure rates.** Of 179 respondents reporting having used at least one of three types of providers (dentist, family doctor, or ER providers), 124 (69%) reported having disclosed their HIV status to all applicable medical providers, and 39 (22%) reported having disclosed to only one or two applicable providers. Sixteen (9%) did not disclose to any of the applicable providers.

Notably, 23 of 202 respondents (11%) reported that they did not use any dental, family medical, or emergency medical services. Of these 23 respondents, 14 (61%) were women, 21 (91%) were African American, and 18 (78%) had CD4 counts  $\geq 200$  cells/mm<sup>3</sup>. Among these 23 respondents, 14 (61%) were African American women, and 11 (48%) were African American women with CD4 counts  $\geq 200$  cells/mm<sup>3</sup>.

Table 2 shows the main effects of gender, racial identification, and CD4 cell count on disclosure to each of three types of provider among those disclosing to that type of

provider. A higher percentage of men than of women reported having disclosed their HIV status to dentists or family doctors, but the gender difference in disclosure rates to ER providers was not significant. White respondents were more likely than African American respondents to report disclosure to dentists, family doctors, or ER providers. Participants with CD4 counts  $< 200$  cells/mm<sup>3</sup> were more likely than those with higher CD4 counts to report disclosure to each of the three types of providers.

Women's rate of disclosure to their ob/gyn providers was very high regardless of racial identification or CD4 count. Seventy-seven (90%) of the 85 women who saw an ob/gyn provider reported disclosing their HIV status to that provider, and no significant differences by racial identification or CD4 count were observed.

**Disclosure rates controlling for CD4 count.** We found differences in disclosure rates by gender and racial

**Table 2. Proportion of respondents who reported having disclosed their HIV status to medical providers, by gender, racial identification, and CD4 count**

Type of provider	n	Characteristic				Estimated RR	95% CI	P
		Men		Women				
		Proportion	Percent	Proportion	Percent			
Dentist . . . . .	139	65/81	80.2	35/58	60.3	1.33	1.05, 1.68	0.013
Family physician . . . . .	137	73/79	92.4	44/58	75.9	1.22	1.04, 1.43	0.013
ER provider . . . . .	150	71/83	85.5	51/67	76.1	1.12	0.96, 1.32	0.148
		White		African American				
		Proportion	Percent	Proportion	Percent			
Dentist . . . . .	139	54/62	87.1	46/77	59.7	1.46	1.18, 1.79	0.001
Family physician . . . . .	137	57/61	93.4	60/76	78.9	1.18	1.04, 1.35	0.027
ER provider . . . . .	150	49/53	92.5	73/97	75.3	1.23	1.07, 1.41	0.009
		CD4 count <200 cells/mm <sup>3</sup>		CD4 count $\geq 200$ cells/mm <sup>3</sup>				
		Proportion	Percent	Proportion	Percent			
Dentist . . . . .	139	57/68	83.8	43/71	60.6	1.38	1.12, 1.72	0.003
Family physician . . . . .	137	59/63	93.7	58/74	78.4	1.20	1.04, 1.37	0.015
ER provider . . . . .	150	68/74	91.9	54/76	71.1	1.29	1.10, 1.52	0.001

NOTE: P values are for two-tailed Fisher's exact tests, comparing those who did and did not disclose to a specific type of medical provider.

RR = relative risk

CI = confidence interval

ER = emergency room

identification when we controlled for CD4 counts. Although a higher percentage of men than of women had low CD4 counts (Table 1), there were no gender differences in rates of disclosure to medical providers among respondents with CD4 counts  $<200$  cells/mm<sup>3</sup>. There were also no differences in rates of disclosure between white and African American respondents in this subgroup (Table 3). However, among respondents with CD4 counts  $\geq 200$  cells/mm<sup>3</sup>, men were more likely than women to disclose to family doctors, and white respondents were more likely than African American respondents to report disclosure to either dentists or family doctors. A higher percentage of white respondents than of African American respondents disclosed to ER providers, but this difference was not significant.

**Multivariate analyses.** Multiple logistic regression analyses identified the variables independently associated with disclosure to each type of medical provider (Table 4). With all three predictor variables in the model, only CD4 count and racial identification were independently associated with disclosure. Respondents with CD4 counts  $<200$  cells/mm<sup>3</sup> were more likely than those with CD4 counts  $\geq 200$  cells/mm<sup>3</sup> to disclose to each type of medical provider, except ob/gyn providers, and white respondents were more likely than African American respondents to disclose to each type of provider, except

ob/gyn providers. Although gender differences were observed with bivariate tests, gender was not independently associated with disclosure in the multivariate analyses.

## DISCUSSION

In this study, 179 respondents reported having used at least one of three providers (dentist, family doctor, or ER providers); of them, 69% reported disclosing their HIV serostatus to all applicable providers. In bivariate tests, we found that those with poorer immune function (CD4 counts  $<200$  cells/mm<sup>3</sup>) were more likely than those with better immune function to report having disclosed their HIV status to dentists, family physicians, and ER providers, and white respondents were more likely than African American respondents to disclose to each of the three types of providers. Women were less likely than men to disclose their HIV status to dentists or family physicians; however, in multivariate analyses controlling for self-reported racial identification and CD4 cell counts, the gender effect dropped out, perhaps because of the significant associations between gender and racial identification and between gender and immune function.

We also identified "racial" differences in rates of disclosure among respondents with better immune function who may have experienced fewer HIV-related symptoms

**Table 3. Proportion of respondents who reported having disclosed their HIV status to medical providers, by gender, racial identification, and CD4 count, controlling for CD4 count**

Type of provider	n	CD4 count $<200$ cells/mm <sup>3</sup>					CD4 count $\geq 200$ cells/mm <sup>3</sup>				
		Men		Women		P	Men		Women		P
		Proportion	Percent	Proportion	Percent		Proportion	Percent	Proportion	Percent	
Dentist. . . . .	139	43/50	86.0	14/18	77.8	0.464	22/31	71.0	21/40	52.5	0.145
Family physician . . . . .	137	43/46	93.5	16/17	94.1	1.000	30/33	90.9	28/41	68.3	0.024
ER provider . . . . .	150	52/55	94.5	16/19	84.2	0.172	19/28	67.9	35/48	72.9	0.794
	n	White		African American		P	White		African American		P
		Proportion	Percent	Proportion	Percent		Proportion	Percent	Proportion	Percent	
Dentist. . . . .	139	27/31	87.1	30/37	81.1	0.742	27/31	87.1	16/40	40.0	$<0.001$
Family physician . . . . .	137	29/30	96.7	30/33	90.9	0.614	28/31	90.3	30/43	69.8	0.046
ER provider . . . . .	150	29/29	100.0	39/45	86.7	0.075	20/24	83.3	34/52	65.4	0.173

NOTE: Proportions represent those who reported having disclosed their HIV status to a particular type of provider divided by those who indicated that they used that type of provider.

ER = emergency room



**Table 4. Variables independently associated with disclosure of HIV infection to medical providers**

Type of provider	Ratio <sup>a</sup>	Percent	R <sup>2</sup>	Odds ratio	95% CI	Significance of Log LR
Dentist						
CD4 < 200 cells/mm <sup>3</sup> . . . . .	57/139	41.0	0.096	3.72	1.60, 8.67	
White . . . . .	54/139	38.8	0.225	4.96	2.01, 12.24	0.0002
Family doctor						
CD4 < 200 cells/mm <sup>3</sup> . . . . .	59/137	43.1	0.086	4.00	1.24, 12.91	
White . . . . .	57/137	41.6	0.155	3.73	1.16, 12.07	0.0168
ER provider						
CD4 < 200 cells/mm <sup>3</sup> . . . . .	68/150	45.3	0.117	4.49	1.68, 12.05	
White . . . . .	49/150	32.7	0.182	3.88	1.24, 12.18	0.0100
Ob/gyn provider (women respondents)						
CD4 < 200 cells/mm <sup>3</sup> . . . . .	23/85	27.1	0.002	0.78	0.15, 4.17	

NOTE: Nagelkerke R<sup>2</sup> indicates the total amount of variation in the dependent variable (disclosed to the provider) that is explained by the logistic-regression model at each step.

<sup>a</sup>Number of respondents with the characteristic who disclosed to the particular type of provider divided by the total number of respondents who reported having used that type of provider.

CI = confidence interval

Log LR = log likelihood ratio statistic

ER = emergency room

than those with lower CD4 counts. Among those with higher CD4 counts, white respondents were more likely than African American respondents to disclose their status to dentists and family physicians. Although the gap in disclosure rates between white and African American respondents was narrower among those with CD4 counts <200 cells/mm<sup>3</sup>, the direction of the difference was the same (Table 3). Finally, in support of one of our hypotheses, self-reported racial identification was independently associated with disclosure to medical providers in the multivariate analyses that included gender, racial identification, and CD4 cell count as predictors (Table 4), with whites reporting disclosure to each type of medical provider (except ob/gyn providers) more frequently than African Americans.

The question remains: why were African American respondents less likely than white respondents to disclose their HIV status to medical providers? There are several potential reasons. Concerns about denial of medical treatment<sup>19,22</sup> and about breaches in confidentiality<sup>19</sup> have been reported. Other reasons center on a general mistrust of the medical community on the part of African Americans.<sup>29,30</sup>

Some analysts believe that African Americans' mistrust of the medical community and government is a legacy of the Tuskegee Syphilis Study, the longest running "non-therapeutic"<sup>29,30</sup> (a euphemism, to be sure) experiment on human beings in medical history. The Tuskegee researchers studied the natural progression of syphilis in 400 African American men from 1932 to 1972, withholding treatment for the disease even after effective penicillin treatment became widely available.<sup>35</sup> African Americans who are HIV-infected may be reluctant to disclose their HIV status to medical providers, particularly those not directly involved in their HIV care, at least in part due to a lingering suspicion of the medical community's intentions to withhold treatment.

The medical community needs to demonstrate that medical injustices like those perpetrated during the Tuskegee experiment are no longer tolerated and that disclosure of one's HIV status to non-HIV medical providers can be beneficial to one's treatment. Culturally sensitive efforts are needed to encourage HIV-infected African Americans to disclose their serostatus to medical providers.<sup>36</sup> It is provocative to think that it may be in some patients' best interest *not* to disclose their HIV

serostatus to medical providers not providing HIV-related care. In a society in which members of minority groups are discriminated against because of their color, African Americans might prefer not to risk further marginalization as a result of disclosing their HIV status and, in some cases, their sexual orientation.<sup>20,21,37</sup> A recent national survey of dentists in Canada reported that nearly 16% of dentists would refuse to treat patients with HIV and that this refusal to treat was significantly related to the belief that they did not have an ethical responsibility to treat patients with HIV.<sup>38</sup> Actual refusal of treatment by doctors and dentists in the United States has been reported by homosexual and bisexual men.<sup>39</sup> Thus, there is still a real basis for the fear that providers will refuse treatment once a patient's HIV serostatus is disclosed.<sup>22,28,40</sup>

Our observation that disclosure occurred more frequently among people with poorer immune function supports another of our hypotheses and corroborates findings from other studies.<sup>20,21,22</sup> For patients with HIV, the benefits of disclosure to their medical providers before they become symptomatic include the availability of services and support throughout the course of the disease.<sup>41,42</sup> Whether the benefits of disclosure before patients become symptomatic outweigh the perceived risks is an empirical question requiring further study.

It is possible that patients' decisions to disclose to their providers was influenced by the gender and "race" of the provider. Patients in our study did not identify providers by gender or "race," so we were not able to address this issue. Other factors may also have been at work; for example, providers with "warm" communication styles with whom patients feel comfortable may be more likely to elicit disclosure of sensitive information than providers with a more neutral or less empathic communication style.<sup>43</sup>

Patients' ages, length of time since diagnosis, and sexual orientation<sup>27</sup> may have added some interesting and important information to our analyses. However, the present paper reports on a secondary analysis of data collected for a study of factors related to patients' use and non-use of specific HIV medications,<sup>31</sup> and data on age, time since diagnosis, and sexual orientation were not available. Future research on disclosure of HIV serostatus to medical providers would benefit from the inclusion of these variables.

There are several factors that limit the generalizability of this study in addition to the delimiting factors described above. First, we used a convenience sample of men and women with HIV who were already receiving HIV medical care. In addition, the sample was not ran-

domly selected nor was it representative of the overall gender or racial distribution of HIV cases in the St. Louis metropolitan area. At the end of June 1996, nearly 88% of the 2571 persons known to be living with HIV disease in the St. Louis metropolitan area were men, and 53% were African American<sup>32</sup>; in our sample, 52% were men and 64% were African American. Nevertheless, our sample included 30% of all of the women known to be living with HIV disease in the St. Louis metropolitan area at the end of June 1996, and an accurate representation of the race distribution among these women.<sup>32</sup> The disproportionate numbers of men and women in our sample reflected our deliberate interest in studying and oversampling women. The overrepresentation of African Americans reflected the higher prevalence of HIV disease in the St. Louis area among African American women (9.5%) than among white (2.6%) or Hispanic (0.1%) women.<sup>32</sup>

In summary, differences by "race" in disclosure, especially among patients who are less severely immunocompromised, suggest a need for public health education of both medical providers and patients with HIV. We recommend that medical providers ask their patients directly about HIV status and that efforts be made to assure patients that their confidentiality will not be breached if they disclose their HIV status to medical providers. Tailored interventions for specific subgroups of patients with HIV should be culturally sensitive and aim to help patients understand that early disclosure of their HIV status to medical providers could help them receive treatments that might prolong and improve their quality of life.

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